Cyborg Pride: Self-Design in e-NABLE

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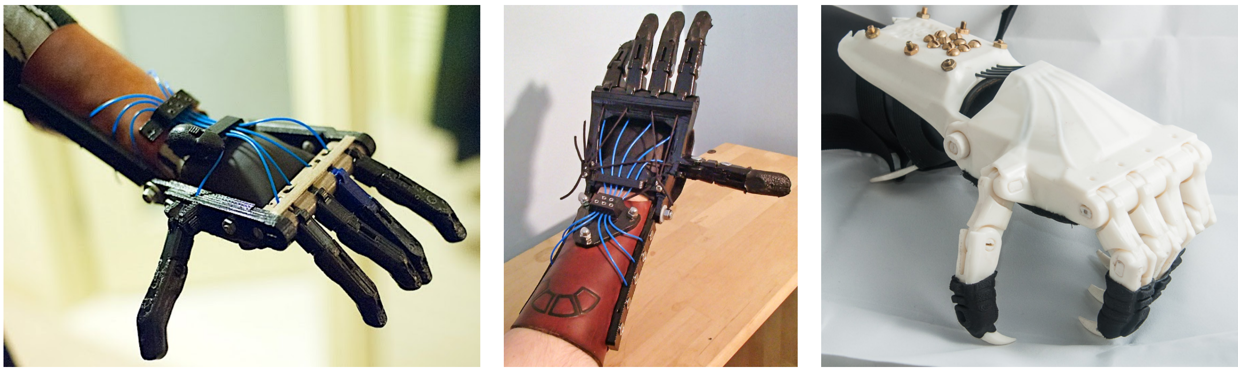

(a) (b) (c)

Figure 1: A partial progression of the first author's hands. (a) Snap-together RoboHand[1] (image courtesy of Jen Owen); (b) Talon hand 3.0[2] (image courtesy Peter Binkley); (c) The hand currently in use, a very highly customized Osprey[3] design.

ABSTRACT

The e-NABLE community is a global, distributed, loosely coordinated effort to design, produce, and deliver upper-limb assistive technology to those in need. e-NABLE's volunteers are often 3D-printing enthusiasts who are driven to use their skills to improve the lives of others. Volunteers provide the devices they produce to recipients around the world; these recipients are mainly children, but some are adults as well. While e-NABLE and its participants have received much attention from the media, little has been written about the experiences of the e-NABLE device users themselves. In this paper, we document the experiences of one user of an e-NABLE hand, detailing in a first-person account the journey from a recipient to an active participant and advocate for self-efficacy.

1. INTRODUCTION

Physical prostheses have been used for thousands of years to replace the function or appearance of a missing body part. Prostheses can be purely—or mainly—cosmetic, aiming to look as much like the original as possible, and can also to varying degrees recreate functionality. Prosthetic technology has always been customized to the end user: while human anatomy naturally varies from person to person, the morphology of missing body parts can vary much more, resulting from congenital factors or injury. While both professionals and amateurs have always created customized assistive technology (AT) [4], in recent years the rise in availability of consumer-level fabrication equipment—especially 3D printers—has allowed for the emergence of a new sharing culture of designs, strategies, and sometimes even physical assistive technology devices themselves.

The e-NABLE community—a globally distributed, loosely organized group of volunteers who design, customize, fabricate, and deliver 3D-printed upper-limb assistive technology to those in need—is a prominent example of this new paradigm of AT production [6]. The devices produced by e-NABLE volunteers combine body-powered functionality with a customizable, but usually non-realistic aesthetic, enabling recipients to grasp and—to a certain extent—manipulate objects while avoiding the traditional "hook" prosthetic.

As yet, there is little published data following up with recipients of these devices to assess the long-term impact of the prosthesis on their lives. It is known from the literature that as many as one in three users of assistive technology may stop using, or abandon, the devices [7], but data specific to e-NABLE is not available. In this report, we add one data point: the first author of this paper is both a recipient of an e-NABLE hand and an active participant in the community. We discuss the experiences of Peregrine with his e-NABLE hands and the community, describing how the device has interacted with and changed his body, life, and sense of self.

1.1 e-NABLE

In earlier work, we described e-NABLE as a community in detail and related some of the challenges that volunteers and clinicians

[1] `https://www.thingiverse.com/thing:92937`
[2] `https://www.thingiverse.com/thing:229620`
[3] `https://www.thingiverse.com/thing:910465`

ASSETS '17, Oct. 29–Nov. 1, 2017, Baltimore, MD, USA.

ISBN 978-1-4503-4926-0/17/10...$15.00.
DOI: `http://dx.doi.org/10.1145/3132525.3134780`

(a) Robohand (b) Phoenix Hand (c) Odysseus Hand (d) RIT Arm with experimental thumb gripper hand

(e) Cyborg Beast (f) Flexy-Hand (g) Raptor Hand (h) Raptor Reloaded

Figure 2: A variety of hands and arms developed in connection with the e-NABLE community. (a) is ⓒ by MakerBot; the other images were taken by the last author at RIT's e-NABLE lab.

encounter when trying to work together [6]. For context, here we will briefly summarize some of those findings, as well as add more detail about the e-NABLE devices themselves.

e-NABLE is primarily represented by a private Google+ online forum (members must request to be admitted, but the acceptance criteria is very liberal). This Google+ community includes over 9,800 members, and continues to grow. Community members can take on any of several roles within e-NABLE, and frequently have more than one role. Potential recipients and parents of recipients participate in the community discussions, as well as general 3D printing hobbyists who are interested in volunteering. Medical professionals, clinicians, and orthotists/prosthetists occasionally lend their expertise to community discussions. Device designers share announcements of new designs with the wider community, and seek volunteers to print new designs on a wide variety of printers for beta testing. A matching team pairs fabricators with recipients. Community organizers announce opportunities to take part in conventions, Maker Faires, and other face-to-face events.

There is no single "e-NABLE device;" rather, the e-NABLE community uses a constantly-evolving array of upper-limb assistive devices. All of these devices share the mechanical property of providing basic grasp assistance and the aesthetic property of appearing—at least to a certain extent—somewhat like a human hand. Although 3D printing is the primary method of producing devices, many designs include a significant portion of non-printed parts. These can include elastic bands, specialized screws, hook-and-loop fasteners, leather, foam padding, and micro gel fingertips. Not all of these components are widely available, leading to design principles around using easy-to-source hardware.

e-NABLE's fabricators provide a number of types of devices that effect a gross grasping motion, using a cable-pull mechanism to cause the fingers to close. Devices are available both for recipients with a transradial or higher amputation ("arms") or wrist or lower ("hands"). For hands—the focus of this experience report—the devices are actuated by wrist flexion.

e-NABLE has a beta testing process for validating candidate device designs, which is documented in the online community. This device validation process includes selecting an appropriate open license, documenting assembly instructions, drafting a bill of materials with sources for all non-printed parts, documenting the results of print tests and user tests, and determining a support plan for questions that may be generated by users. All of this documentation is then submitted to e-NABLE's Strategic Planning Committee for approval.

When a device design is approved for wide release, source files are posted to a publicly-accessible repository, such as Thingiverse[4] or Youmagine[5]. A link to the design is added to the list of devices on the e-NABLE website[6], and announcements of the new design are posted to the Google+ e-NABLE community.

Figure 2 shows a number of the hands and arms that have been developed in connection with the e-NABLE community.

2. RELATED WORK

Beyond our own work [6], discussed above, the e-NABLE community, its members, and the technology it produces have been a topic of some academic interest. With reference to the e-NABLE community itself, Homan et al. used textual and network analysis techqniues to comment on the origins and evolution of the Google+ online forum [3].

From a clinical perspective, some effort has been focused on the "development of the 3D-printed devices as well as considerations around actual production. Zuniga et al. have published several papers on construction and fitting of e-NABLE devices [10, 11, 9], including a brief report on one to three months of usage by eleven children. The authors found that using the device correlated to some improvement in life quality, and that the amount of use varied considerably. Researchers have also taken advantage of the customizability of 3D-printed technology to rapidly prototype task-specific prosthetic devices, such as a violin bow holder [2].

[4]http://www.thingiverse.com
[5]https://www.youmagine.com/
[6]http://enablingthefuture.org/upper-limb-prosthetics

Hofmann et al. reported on the perspectives of e-NABLE-involved clinicians and makers who attended an e-NABLE summit. They noted the tensions between the clinicians' "do no harm" professional ethical stance and the makers' desire for rapid iteration and unbridled creativity [1].

Some researchers have investigated the experiences of end users of personalized assistive technology. Profita et al. investigated the customization activities of hearing aid and cochlear implant users, finding that device wearers saw decorating their devices as a medium for self-expression [8]. Similarly, Bennett et al.'s study of 14 individuals with upper-limb difference showed that those who chose to use prostheses integrated them as part of their self-identity, often enhancing this effect by aesthetic customization. In an interesting contrast to the first author of this paper, Bennet et al.'s study included five e-NABLE recipients, none of whom used their 3D-printed—or any—prosthesis with regularity.

Finally, Meissner et al. described a series of workshops intended to give people with disabilities an opportunity to learn and use making skills by themselves [5]. They found that participants were interested in learning and exercising skills and in building technology to help themselves and others—interests that mirror our own findings of motivations of volunteers in e-NABLE [6].

3. THE EXPERIENCE OF AN E-NABLE DEVICE USER

In this section, the first author provides a first-person account of his experiences as an e-NABLE user, community participant, and advocate for self-efficacy for people with disabilities.

3.1 Early Experience

My name is Peregrine Hawthorn, and I was born without fingers on my left hand. Growing up, I was often ridiculed for my difference, and made to feel physically inferior to all my peers. My family was poor, so we never considered any sort of assistive technology.

It wasn't until I was 18 years old, after I had graduated from high school, that I discovered 3D printing, and the ability to create my own set of fingers. My father was the first to get a 3D printer—the Solidoodle 2—and it was an ordeal to get successful prints out of it, but after about 3 months of modifying and fiddling with the printer, we managed to print and assemble a Snap-Together Robohand (Figure 2a). I very quickly got used to having an extra five fingers, and I often found myself trying to, and sometimes failing to, resist the urge to grab something simply because I now could. Since I put on my first hand, it's been an integral part of who I am and what I do. Today, I design and build hands, in addition to wearing and using them.

The first hand I made (Figure 1a) provided a fantastic experience, but was sub-par on almost every level. Before we could even make a hand, we had to change designs from the "official" Robohand to the Snap Together Robohand released my Makerbot, due to the fabrication instructions being incomplete and referencing parts not included in the design files. Once we assembled a functional hand, it was bulky and didn't fit me very well. The forearm was small and inflexible, and the plastic wrist joints didn't line up well with my wrist. I couldn't use it to do more than to gesture or to drag a small amount of weight, as too much pressure would start to warp the palm. It hurt to wear for more than a few hours at a time because the cable guides in the forearm and back of the hand weren't fixed in place, causing them to turn and dig into my arm under physical stress.

One of the earliest modifications to the hand involved using a hacksaw. The original RoboHand's attachment to the wrist involved two parallel bars, which doesn't fit well on adults. We cut off parts of the knuckle block to make the sides slope in towards my wrist. We also dipped the ends of the palm and the arm bars in boiling water to soften them and bent them with pliers to give me a better fit. However, where the physical function was lacking, we were able to customize my new hand to my liking, with stamped leather and glossy black fingers to give a "Darth Vader" feel to my new fingers. Despite having no prior experience 3D printing, we were able to construct a rudimentary hand from my fathers experience with other materials like leather and thermoplastics: skills I quickly picked up as I did further post-print modifications and repairs on subsequent hands.

Once my hand became comfortable enough that I could use it to lift more than a couple of pounds, with the addition of padding and slightly more rounded corners, I began losing fingers about as fast as we could print replacements. A combination of poor print quality and thin, delicate parts meant that the finger joints would break frequently, sometimes without me even noticing until hours later. This would be fixed, mostly by identifying weak points by fractures and bulking them up until they stopped breaking. This was a clumsy method, but effective within the confines of what I was capable of. The more elegant changes came later when I started fusing parts that didn't need to be printed separately anymore because of desktop 3D printing advancements allowing for greater overhangs and sturdier layer adhesion.

Most of the early modifications happened on the design file end, and the bulk of those were done by my father, the far more experienced 3D modeler among us. However, most of those early changes were informed by my use and suggestion. Until I learned to use modeling programs like Blender, TinkerCAD, Solidworks, and Fusion 360, I mostly made post-printing modifications like finding better materials for finger pads, or using different metal hardware that allowed me to more easily make adjustments on the fly. All the modifications we made for durability, we devised ourselves, as no one else in e-NABLE had much experience with parts breaking. However, we did pull some structural inspiration from models like the Cyborg Beast for my eventual plastic upper, as well as 3D printed washers for large snap pins in the wrist to replace steel bolts with nylock nuts I continually lost.

Shortly after I got my first hand, I began working. I worked backstage at a local theater, building sets, assisting quick changes, and fixing broken microphones during the show. After that, I worked for Fed-Ex sorting packages. After that, I joined Americorps NCCC, FEMACorps, and traveled around the country aiding disaster recovery efforts in Oklahoma, Northern Texas, and Southern California. Upon graduation out of the AmeriCorps program, I worked in event setup, creating and setting up decor for weddings and events, doing everything from moving very large base plates to building centerpieces.

Each and every one of these jobs was a testing ground for the latest iteration of my limbs. Each step of the way I improved the base features of my hand like bulking up fragile parts or using better grip material as I found it, or making the fit more dynamic and adaptable to different amounts of clothing or fitting around uniforms. Most of these modifications were made to the original design files in Blender, which I learned from my father and online tutorials. I also would make regional or task-specific changes to match different jobs, like attaching a flashlight to my wrist when working backstage, making my hand able to convert into a hip water bottle holder in AmeriCorps, or insulating my fingers with rubber to allow me to unravel yard upon yard of cord, and change light-bulbs on live wire without the risk of electrocution. Later I would also thicken portions of my hand that I intended to use as a hammer, and add claws that allowed me to manipulate very small objects when building prototype electronics. These modifications were usually made post-print, or made quickly in easier to use, but less powerful, modeling software like TinkerCAD.

Relatively early on in this adventure, I was contacted by Ivan Owen, the maker who designed the original Snap-Together Robohand. We were both in the Seattle area at the time, and after meeting up and sharing our stories, he directed me to a group on Google+ called e-NABLE. e-NABLE is an online group of people from around the world who had taken an interest in developing and distributing 3D printed upper limb prostheses. Many of the designs were highly temperamental, but some of the early ideas in that community became instrumental in the later development of upper limb prostheses today. I quickly found a place in this community as one of the most vocal and articulate users of the devices developed there.

3.2 About My Hand

In my experience designing and using upper limb assistive technology, the most important thing is that it be comfortable. This means that it is not only easy on the user when they are at rest or preforming light actions, but when they are under the greatest stress that they can expect to endure. It is not enough to be comfortable in the lab, when it's first put on. It must continue to be comfortable in heat and cold, while carrying significant weight, and under sustained use.

To fulfill these requirements when designing and building a hand, I prefer to use leather as a base, and either foam or silicone for padding. Despite the trademark aspect of my assistive devices being that they are 3D printed, to avoid abrasion issues I don't let any of that printed plastic touch my skin. I remain separated from the plastic by a thick layer of leather, secured in place with machine screws into the plastic and with nylon straps and tri-glide adjusters (Figure 3).

The general construction of my prosthetic devices has changed only slightly in the years that I've been wearing them. All custom parts are 3D printed in ABS plastic in a fused deposition printer. I then sand those parts to remove any stray bits of plastic, hold them at approximately 110°C to improve layer adhesion and overall strength, and then expose them to a cloud of acetone vapor to vitrify and smooth over the rough print lines. This makes the otherwise porous and rough surface strong, smooth, and easy to keep clean. I then mount these parts to leather with either machine screws (newer hands) or rivets (older hands). Leather is a fantastic material here, because it's very easy to use, and is significantly more comfortable than any printed plastic structure. Braided actuator cables are sometimes tied to screws or printed bars, but I prefer to use nylon monofilament cables that I affix with set screws in the forearm and fingers. Originally this preference was purely aesthetic, but this later became the foundation of how I removed elastics from the actuation system, relying on stiffer cabling that both close and open my fingers.

Form and function play an integral role in my relationship with my prosthetic hands. This is also true for e-NABLE recipients: among child users, I observe them often preferring a particular look over usefulness or durability. This makes sense, as they often use 3D printed limbs on a social level, rather than a physical one. It is far more important that their limb be a "character-themed hand" than that it be able to carry lots of weight for long hours. In the future, it would be nice if hand designs allowed for more customization, beyond the colors parts are printed in. I could see space for designs or a signature being useful in helping a device feel more like a part of the user. Other small customizations like a slot for frequently used items, or decorative attachments have had some success, but they've been few and far in-between, and none have been seen as more than just a novelty one-off device.

Despite its importance, this kind of personalization can often be hindered by a social barrier. If a volunteer is making a hand, free of charge, it's not uncommon for a recipient to feel like any requests are imposing and taking advantage of the kindness of others. It can be considered charity work, not a business, and as such the recipient may not feel entitled to ask for much customization. This issue can be exacerbated by the fact that most users are young enough that most communication passes through their parents on its way to an e-NABLE volunteer, and thus most possibility for creative expression is dulled across communication channels.

When I create my own limbs, there is no such barrier: I can spend as much time and effort on them as I like (Figure 3). I have rubber work glove parts on my fingers and large claws simply because I wanted to try it out and thought it might look nice; they turn out to be useful for holding different kinds of objects and for pulling sleeves and gloves onto my unaffected hand. I put protruding bolts on my bracer because I felt the extra strength they might provide would be worth the sharp edges. I used three different methods to affix my actuator cables into my fingertips because I was tired of them popping out under excessive strain. I worked for a few hours just to create the aesthetic design on the back of the piece that I felt I should have there. I experimented with steel brushes to give the white plastic the look of bone. I even printed finger connector pins in three different colors so I could coordinate them with my clothing. In my customization, I went far beyond what I would ever consider asking anyone else to do for me, particularly if I felt somehow indebted to them for this service.

It has been my observation that, as all e-NABLE hands are made for printing and assembly by inexperienced DIY "makers" or others of similar skill level, any hand that can be successfully distributed must be made of easily acquirable parts, such as those that can be purchased at a hardware store. Generally, a low-end 3D printer is the only piece of specialized equipment we can expect anyone to have access to. This dramatically reduces the variety of solutions available for designing DIY assistive technology. This means that, as a designer, I need to make everything easy to source, fit, and make, as well as make every design robust against failure from many angles. My personal hand uses metal hardware, leather, nylon straps, heavy gauge fishing line, and rubber work gloves. I deliberately chose all of these as easy to find and easy to work with. The digital files for my hand also contain many variations of the same part with different levels of joint tolerance, to accommodate for scale and to correct for low quality printers' tendency to over-extrude.

For me, and for many others, the hand and all of the modifications are not just about function, but about the social aspect, especially for kids. In school, most children haven't yet learned yet how to be decent human beings, and they will pick on any differences they can find. If you can go from being the kid with the weird hand to the kid with the cool robot hand, you can go from being an outcast to the kid everyone wants to be friends with. In that way, the social aspect can be even more important than the functionality of the hand.

3.3 Cyborg Identity

My own social experience as a congenital amputee has been a generally troubled one. Mostly through between the grades of one and four, I was consistently made fun of and considered "other" by my peers. However, beyond that, most people either made a point of ignoring or simply didn't notice my limb difference. I also got very good at hiding it, always covering my affected hand in photos and wearing baggy long sleeve shirts that covered my affected limb. It wasn't until I was 18 and made my first assistive hand that I began

Figure 3: Images of Peregrine's current hand with its modifications. Left: claws allow fine manipulation and the ability to pull on sleeves and gloves on the right hand. Center: crossed straps provide a more comfortable fit than a single one. Right: a close-up image of the aesthetic customizations, including brass hardware, protruding bolts, and gear-shaped finishes.

to display my hand again. Now I don't hide my hand partly because, physically, I can't. The device I wear is too big to fit in any pocket, and eclipses my unaffected hand. However, the more prominent reason I display my prosthetic hand is because of the role I had in making and designing it, and how happy I am with the results. Every assistive device I've worn highlights my limb difference. Because of this, every hand I wear is designed to celebrate that difference. My first hand was a glossy black with bright blue actuation cables. Today my hand is bright white to contrast with the black I usually wear, further putting my hand in the spotlight, and has symbols of personal significance embossed into the forearm that mirror a necklace given to me.

As someone who grew up with depression, it had always been difficult to associate with myself. I rarely had any strong feelings about things happening to me, and never had much interest in self-improvement. The only things I ever got excited about were things I had made. I would go far out of my way to find and hoard scrap and raw material to make things with. When I began to make my own limbs, I became my own project. I became a prototype to be refined as I use, break, repair, and redesign my body—my self.

Today, I feel a responsibility for my own body parts. I am able to be independent and to maintain myself. If part of my hand breaks, I don't have to ask someone else to fix it. I have an understanding of how it works and what its limitations are. I can upgrade myself as needed, and I can see the same thing happening for other people: in the future, they might design their own hands to specialize them to what they want to do, whether it is fine-grained manipulation, holding a glass of wine, or moving heavy boxes around.

I see myself as a work in progress, and as something worthy of of improving and upkeeping. I think this is one of the greatest things that someone could get out of this experience: not just the hand, but the idea that you are worth improving, and that you have the ability to improve yourself.

Acknowledgements

This material is based upon work supported by the National Science Foundation under Grant No. IIS-1464377.

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